

**NPM 01:** *The percent of newborns who are screened and confirmed with condition(s) mandated by their State-sponsored newborn screening programs (e.g. phenylketonuria and hemoglobinopathies) who receive appropriate follow up as defined by their State.*

| Annual Objective and Performance Data | Tracking Performance Measures<br>(Sec 485 (2)(2)(B)(iii) and 486 (a)(2)(A)(iii)) |      |       |       |       |
|---------------------------------------|--|------|-------|-------|-------|
|                                       | 2000   | 2001 | 2002  | 2003  | 2004  |
| Annual Performance Objective          |  |      |       | 100   | 100   |
| Annual Indicator                      |  |      | 100.0 | 100.0 | 100.0 |
| Numerator                             |  |      | 84    | 95    | 124   |
| Denominator                           |  |      | 84    | 95    | 124   |
| Is Data Provisional or Final          |  |      |       | Final | Final |
|                                       | 2005   | 2006 | 2007  | 2008  | 2009  |
| Annual Performance Objective          | 100  | 100  | 100   | 100   | 100   |

#### Notes - 2002

Source: Numerator: NBS program, State Lab of Hygiene, Wisconsin, 2002. The number of infants that were confirmed with a condition through newborn screening that receive appropriate follow-up care. Denominator: NBS program, State Lab of Hygiene, Wisconsin, 2002. The number of infants confirmed with a condition through newborn screening. This performance measure focuses on whether state newborn screening programs are ensuring that infants picked up on newborn screening are receiving appropriate follow-up care. The old Performance Measure #4 measured the percentage of infants born in the state and screened by newborn screening.

#### Notes - 2003

Source: Numerator: NBS program, State Lab of Hygiene, Wisconsin, 2003. The number of infants that were confirmed with a condition through newborn screening and who receive appropriate follow-up care. Denominator: NBS program, State Lab of Hygiene, Wisconsin, 2003. The number of screened through NBS and confirmed with a condition. Wisconsin screens for 26 congenital disorders. Every newborn with an abnormal NBS result is tracked by the NBS Program to a normal result or appropriate clinical care.

#### Notes - 2004

Source: Numerator: NBS program, State Lab of Hygiene, Wisconsin, 2004. The number of infants that were confirmed with a condition through newborn screening and who receive appropriate follow-up care. Denominator: NBS program, State Lab of Hygiene, Wisconsin, 2004. The number of screened through NBS and confirmed with a condition. Wisconsin screens for 26 congenital disorders. Every newborn with an abnormal NBS result is tracked by the NBS Program to a normal result or appropriate clinical care.

#### a. Last Year's Accomplishments

Impact on National Outcome Measures: The Wisconsin NBS Program is a core public health program that is a collaborative effort between DHFS and the State Lab of Hygiene. The NBS Program specified in Wis. State Statute 253.13 and Administrative Rule HFS 115, is a population-based service that mandates all infants born in Wisconsin be screened for congenital disorders.

## Report of 2004 Major Activities

### 1. Newborn Screening--Population-Based Services--Infants

In 2004, 68,894 infants were screened for 26 different congenital disorders.

### 2. Diagnostic Services--Direct Health Care Services--CSHCN

In 2004, 124 infants were confirmed with a condition screened for by the NBS Program, and 100% were referred for appropriate follow-up care.

### 3. Diagnostic Services--Direct Health Care Services--CSHCN

The Department provides necessary diagnostic services, special dietary treatment as prescribed by a physician for a patient with a congenital disorder and follow-up counseling for the patient and his or her family.

### 4. Development of Educational Materials--Enabling Services--Mothers and Infants

The Education subcommittee of the NBS Advisory Group produced fact sheets for genetic counseling of families of infants identified with galactosemia, sickle cell trait, hemoglobin D trait, hemoglobin C trait, as well as cystic fibrosis carriers. The fact sheets are available to healthcare professionals throughout Wisconsin to provide patient education and genetic counseling to families.

### 5. Newborn Screening--Infrastructure Building Services--Infants

The "Wisconsin-Family Symposium of Newborn Screening for the Amish and Mennonite Populations" brought together stakeholders from DPH, the State Lab of Hygiene, the University of Wisconsin Waisman Biochemical Genetics Clinic, as well as midwives, care providers in the Amish and Mennonite communities, and families from within the Amish and Mennonite communities. Participants at the symposium had the opportunity to dialogue regarding building systems of care that reach the growing Amish and Mennonite populations in WI with NBS services.

| Activities   | Pyramid Level of Service |    |     |    |
|--|--------------------------|----|-----|----|
|  | DHC                      | ES | PBS | IB |
| 1. Newborn Screening                                   |                          |    | X   |    |
| 2. Diagnostic Services - Infants                       | X                        |    |     |    |
| 3. Diagnostic Services - Congenital Disorders          | X                        |    |     |    |
| 4. Development of Educational Materials                |                          | X  |     |    |
| 5. Newborn Screening - Amish and Mennonite Populations |                          |    |     | X  |

## **b. Current Activities**

### 1. Newborn Screening--Population-Based Services--Infants

The Wisconsin NBS Program currently screens all infants for 26 congenital disorders.

### 2. Newborn Screening Advisory Group--Infrastructure Building Services--Infants

The NBS Advisory Group and its Cystic Fibrosis, Metabolic, Hemoglobinopathy, and Endocrine subcommittees are developing action plans for expected follow-up activities in the newborn screening lab when a "possible" or "definite" abnormal result is obtained to ensure that all available resources are utilized to locate infants and arrange for necessary follow-up testing.

3. Region 4 Genetics Collaborative--Infrastructure Building Services--Infants

The Wisconsin NBS Program is participating in the HRSA "Region 4 Genetics Collaborative" grant. The regional collaborative allows states to share expertise in new technologies and best practice models to maximize available newborn screening resources.

4. Newborn Screening--Infrastructure Building Services--Infants

The State Lab of Hygiene is developing a protocol for NBS of Mennonite infants known to be at risk for MSUD, to optimize the screening and diagnostic process and decrease time to treatment for affected infants.

**c. Plan for the Coming Year**

1. Newborn Screening--Population-Based Services--Infants

All infants born in Wisconsin will be screened at birth for a minimum of 26 congenital disorders.

2. Newborn Screening Advisory Group--Infrastructure Building Services--Infants

The Newborn Screening Advisory Group and its Cystic Fibrosis, Metabolic, Hemoglobinopathy, Endocrine, and Education subcommittees will meet biannually to advise the Department regarding emerging issues and technology in NBS.

3. Newborn Screening Education--Enabling Services--Mothers and Infants

The NBS Advisory Group Education subcommittee will pilot a project to increase parental awareness of NBS at the time of the heel stick. The project will involve providing birthing hospitals with stickers containing a NBS message that may be affixed on or near an infant's bassinet at the time of the heel stick to alert parents that the blood draw for the NBS test has been completed.

4. Purchase of PKU Formula and Food Products--Direct Health Care Services--CSHCN

The Department will develop a web-based data tracking system for NBS dietary services, including the provision of dietary formulas and medical food products to children with conditions screened for by NBS to more effectively monitor use of this service.